

Conclusions of Dorothee Schmid, a longterm survivor, on occasion of the „International Symposium on Past Successes & Future Challenges in Pediatric Oncology“, 15.-17. May 2008, Vienna

Education

Society should learn a few facts about cancer within children:

- Cancer can also occur within children.
- Cancer within childhood is more easily cured than in later stages of life; currently the survival rate, depending on type of cancer, lies above 75% percent thus 3 out 4 diseased children can become longterm survivors of cancer.
- However, in Europe cancer amongst children and adolescents is still the second highest cause of death for children (after casualties).
- Most children/adolescents can lead a normal life after having had cancer. However, they must live with several disabilities, they have physical and or psychological longterm effects (reduced resilience, problems of attention and concentration, physical disabilities such as amputations, an increased risk of a new outbreak and or relapse etc.)

Perception/handling

How former patients of children`s cancer want to be treated and perceived during adolescence and adulthood by friends, acquaintances, strangers as well as doctors:

- "As normally as possible - with as much consideration as necessary".
- We can decide for ourselves what we are still and what we are not anymore capable of.
- We want the same chances, possibilities, rights as our peers (within professional life as well as within insurance).
- We require honest explanations by our doctors, in age appropriate manner and language.

Aftercare

Wishes/expectations from medical and psychosocial aftercare:

- We want to know we are in good medical hands, even years after the affection (our doctors should know about longterm effects).
- We want to know who carries responsibility of access to regular aftercare examinations.
- We want to know who can turn towards with medical concerns (children's oncology, adult oncology, general hospital, doctor's practice).
- We have very specific questions for our doctors (eg. fertility or during pregnancy or for our children).
- We want to know for how long we need to go to check-ups.
- Some former children's cancer patients like to call upon psychosocial aftercare programmes and desire the exchange with others, some don't. Thus, such programmes should be offered, but should remain voluntary choices.

- We consider psychosocial aftercare, such as the rehabilitation clinics, youth groups, young people's seminars etc., are incredibly important for the development of children/young adults having overcome cancer for the following reasons:
 - During the disease we feel lonely and as though having an "exotic" illness, feeling outcast. In youth groups, rehabilitation stay, leisure programmes one gets to know peers with the same or similar condition and feels more "normal".
 - Our self-confidence can be re-built and we can discover what we are (still) capable of and where our limitations lie.
 - Through longterm treatment of the disease one becomes isolate from the outside world for a long time. In youth groups we can "learn" a lot, we can meet interesting people and form new friendships. It helps us accept a place within society.